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***Cruzan's* Legacy in Autonomy**

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CRUZAN'S LEGACY IN AUTONOMY

Kathy L. Cerminara*

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I. INTRODUCTION

THE Supreme Court in *Cruzan v. Director, Missouri Department of Health*¹ effectively enshrined personal autonomy in a medical setting as a constitutionally protected liberty interest. Although the majority opinion only “assumed” the right’s existence,² Justice O’Connor, writing in concurrence, and four other Justices writing in dissent explicitly found that the right existed.³ In a later opinion about medical decision-making, the Court described itself as having “assumed, and strongly suggested” the right’s existence in *Cruzan*.⁴ Certainly, the majority opinion stated in dicta that “[t]he principle that a competent person has a constitutionally protected liberty interest in refusing unwanted medical treatment may be inferred from our prior decisions,”⁵ thus laying a solid foundation upon which to base a conclusion that such a constitutionally protected liberty interest existed.

The various opinions in *Cruzan*, however, disagreed about the shape and boundaries of the right. In the case’s immediate aftermath, the federally recognized right to exercise autonomy in medical decision-making

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1. *Cruzan v. Dir., Mo. Dep’t of Health*, 497 U.S. 261, 262 (1990).

2. *Id.* at 279.

3. *Id.* at 287, 289 (O’Connor, J., concurring); *id.* at 302 (Brennan, J., dissenting, joined by Marshall and Blackmun, JJ.); *id.* at 331 (Stevens, J., dissenting).

4. *Washington v. Glucksberg*, 521 U.S. 702, 720 (1997).

5. *Cruzan*, 497 U.S. at 278 (majority opinion) (characterizing this statement as dicta); see also ALAN MEISEL ET AL., *THE RIGHT TO DIE: THE LAW OF END-OF-LIFE DECISION-MAKING* § 2.03[A][2], at 2-10 (3d ed. 2004).

faced two divergent paths. The majority and Justice O'Connor's concurrence spoke of the right as rooted in the common-law doctrine of informed consent, and the Supreme Court later, in *Washington v. Glucksberg*, echoed that approach.⁶ In contrast, Justice Stevens, writing in concurrence, envisioned a more expansive view of autonomy, one that not only encompassed a right to say "no" to bodily intrusion, but also honored the right to say "yes"—to make decisions regarding one's body and the condition in which one would wish to live.⁷ The latter conception of the right is more true to the origins of the doctrine of informed consent upon which the majority relied, given that the roots of informed consent grew from a desire to ensure patients' receipt of adequate knowledge to make decisions, both affirmative and negative.⁸

Since *Cruzan*, the right to personal autonomy in decision-making has continued to develop along both paths. In *Glucksberg*, the Supreme Court considered it a right to say "no," based on Justice O'Connor's conception in *Cruzan*, but it did so by rephrasing the right as something other than medical decision-making. *Glucksberg* involved claims by physicians and terminally ill patients that state laws prohibiting assisted suicide were unconstitutional when applied to terminally ill patients with decision-making capacity who sought prescriptions to cut short their dying processes.⁹ The Court did not even consider the case before it as involving a right to make medical decisions; the majority decided the case by examining whether a federal constitutional "right to suicide" existed.¹⁰ *Cruzan* and *Glucksberg* represent the extent to which the Court has addressed end-of-life medical decision-making, but other courts since have recognized a more expansive conception of autonomy than the one recognized by the *Cruzan* majority.¹¹

The Supreme Court has adopted the more inclusive view of autonomy in other areas of constitutionally protected decision-making since *Cruzan*. In *United States v. Windsor*,¹² the Court held unconstitutional the federal Defense of Marriage Act,¹³ whose effects it said were "to demean" those

6. *Cruzan*, 497 U.S. at 277 (majority opinion); *id.* at 287 (O'Connor, J., concurring); *id.* at 293 (Scalia, J., concurring); *see also Glucksberg*, 521 U.S. at 725 (describing *Cruzan* as establishing no general "right to die" "deduced from abstract concepts of personal autonomy"); *id.* at 727 (rejecting proposition that citizens have protected liberty interests in "all important, intimate, and personal decisions").

7. *See Glucksberg*, 521 U.S. at 799 (Stevens, J., concurring); *see also MEISEL ET AL.*, *supra* note 5, § 2.03[B], at 2-13.

8. As Justice Cardozo explained in 1914, "Every human being of adult years and sound mind has a right to determine what shall be done with his own body" *Schloendorff v. Soc'y of N.Y. Hosp.*, 105 N.E. 92, 93 (N.Y. 1914).

9. *Glucksberg*, 521 U.S. at 705-09 (majority opinion).

10. *Id.* at 723.

11. *See, e.g., Baxter v. State*, No. ADV-2007-787, 2008 Mont. Dist. LEXIS 482, at *35 (Mont. Dist. Ct. Dec. 5, 2008), *aff'd in part, vacated in part, rev'd in part*, 224 P.3d 1211 (Mont. 2009) (trial court ruling—vacated but not overruled—that state constitution provided a right); *see also Carter v. Canada*, [2015] 1 S.C.R. 331 (Can.) (construing Canadian Constitution).

12. 570 U.S. 744 (2013).

13. *Id.* at 751-52.

it affected.¹⁴ A law with “the power to degrade or demean” those it affected was unconstitutional as a deprivation of the constitutional interest in personal liberty.¹⁵ In *Obergefell v. Hodges*,¹⁶ the Court similarly struck down states’ refusals to recognize gay marriage. The Court held the state statutes at issue to be unconstitutional as violations of the constitutional liberty to make “certain personal choices.”¹⁷ It held that the Constitution protected the decision to marry because that decision “is among life’s momentous acts of self-definition.”¹⁸ The right the Supreme Court protected in both *Windsor* and *Obergefell* was the right to make “certain personal choices central to individual dignity and autonomy, including intimate choices that define personal identity and beliefs.”¹⁹

This article considers the Court’s divergent paths of analysis with respect to three types of end-of-life medical decision-making occurring more and more frequently as medical knowledge grows. It addresses three areas in which clinical boundaries have moved since the time of *Cruzan*, each of which will help define autonomy to make end-of-life medical decisions in the future. Surrogate refusal of medically supplied nutrition and hydration was at issue in *Cruzan* and now is well-accepted; surrogate refusal of food and water administered by mouth is coming. *Cruzan* involved surrogate refusal of end-of-life treatment of a patient in a persistent vegetative state (PVS), now well-accepted. Issues increasingly will arise regarding surrogate refusal of such treatment when a patient is in a minimally conscious state (MCS). Finally, at the time of *Cruzan*, it generally appeared that “death is death.”²⁰ Now, clinicians are facing increasing surrogate decisions blocking the removal of brain-dead patients (patients dead by neurological criteria) from maintenance.

II. FROM NUTRITION AND HYDRATION TO FOOD AND WATER

One important facet of *Cruzan* was that the medical treatment Ms. Cruzan’s family sought to withdraw was medically supplied nutrition and hydration administered through a PEG tube directly into Ms. Cruzan’s body. *In re Quinlan*,²¹ the seminal case involving the right to refuse life-sustaining treatment, and many other similar cases involved removal of

14. *Id.* at 774.

15. *Id.*

16. 135 S. Ct. 2584 (2015).

17. *Id.* at 2597.

18. *Id.* at 2599 (quoting *Goodridge v. Dep’t of Pub. Health*, 798 N.E.2d 941, 955 (Mass. 2003)).

19. *Id.* at 2597–98 (citing *Eisenstadt v. Baird*, 405 U.S. 438, 453 (1972); *Griswold v. Connecticut*, 381 U.S. 479, 484–86 (1965)). See generally Melissa Legault, “*I Don’t Want to Die, But I Am Dying*”: Reexamining Physician-Assisted Suicide in a New Age of Substantive Due Process, 60 ARIZ. L. REV. 509, 522 (2018) (describing the Court’s jurisprudence as moving “toward a renewed appreciation for personhood, autonomy, and dignity”).

20. See Alice D. Ackerman, *Death is Death: Isn’t It?*, 45 CRITICAL CARE MED. 1579, 1579–80 (2017).

21. 355 A.2d 647 (N.J. 1976).

respirators,²² and a respirator is readily understood to be life-sustaining treatment.²³ In contrast, the Court in *Cruzan* had to decide whether medically supplied nutrition and hydration was life-sustaining treatment. Although many pre-*Cruzan* courts had considered it to be medical treatment capable of being withheld or refused,²⁴ *Cruzan* provided an opportunity to learn whether the Supreme Court agreed. Five Justices did agree,²⁵ affirming the predominant secular view of the matter.²⁶

For example, Justice O'Connor wrote: "I agree that a protected liberty interest in refusing unwanted medical treatment may be inferred from our prior decisions, and that the refusal of artificially delivered food and water is encompassed within that liberty interest."²⁷ She further explained that "[a]rtificial feeding cannot readily be distinguished from other forms of medical treatment."²⁸ While focusing primarily on the degree of bodily invasion medically supplied nutrition and hydration causes rather than on precise classification as treatment, she nevertheless concluded that "the liberty guaranteed by the Due Process Clause must protect, if it protects anything, an individual's deeply personal decision to reject *medical treatment, including the artificial delivery of food and water*."²⁹

Justice Brennan explicitly addressed why medically supplied nutrition and hydration constituted medical treatment. While he wrote in dissent from the Court's holding, he, Justice Marshall, and Justice Blackmun, who joined his opinion, were three of the five Justices constituting a majority that concluded that medically supplied nutrition and hydration was medical treatment. Brennan explained:

The artificial delivery of nutrition and hydration is undoubtedly medical treatment. The technique to which Nancy Cruzan is subject—artificial feeding through a gastrostomy tube—involves a tube implanted surgically into her stomach through incisions in her abdomi-

22. *Id.* at 655.

23. MEISEL ET AL., *supra* note 5, § 6.03[E], at 6-64 (describing ventilators, commonly called respirators, as "devices that assist patients in breathing").

24. *See id.* § 6.03[G][5], tbl. 6-82.4-6-82.8 (listing cases, many both before and after *Cruzan*, involving medically supplied nutrition and hydration).

25. *Cruzan v. Dir., Mo. Dep't of Health*, 497 U.S. 261, 265 (1990).

26. Roman Catholic health care facilities are bound to follow guidelines set forth by the American Conference of Catholic Bishops, which consider medically supplied nutrition and hydration to be "ordinary" care that cannot be withdrawn or withheld. *Compare* Congregation for the Doctrine of the Faith, *Responses to Certain Questions of the United States Conference of Catholic Bishops Concerning Artificial Nutrition and Hydration*, HOLY SEE (Aug. 1, 2007), http://www.vatican.va/roman_curia/congregations/cfaith/documents/rc_con_cfaith_doc_20070801_risposte-usa_en.html [<https://perma.cc/N8J2-ZFQE>], with WILLIAM H. COLBY, LONG GOODBYE: THE DEATHS OF NANCY CRUZAN 137 (2002) (noting that all medical groups considered medically supplied nutrition and hydration to be medical treatment, according to neurologist Dr. Ronald Cranford).

27. *Cruzan*, 497 U.S. at 287 (O'Connor, J., concurring) (citation omitted).

28. *Id.* at 288 (citing COUNCIL ON ETHICAL AND JUDICIAL AFFAIRS, AM. MED. ASS'N, ETHICAL OP. 2.20, WITHHOLDING OR WITHDRAWING LIFE-PROLONGING MEDICAL TREATMENT 13 (1989); NANCY BERLINGER ET AL., THE HASTINGS CTR., GUIDELINES ON THE TERMINATION OF LIFE-SUSTAINING TREATMENT AND THE CARE OF THE DYING 59 (1987)).

29. *Id.* at 289 (emphasis added).

nal wall. . . . Typically, and in this case, commercially prepared formulas are used, rather than fresh food. The type of formula and method of administration must be experimented with to avoid gastrointestinal problems. The patient must be monitored daily by medical personnel as to weight, fluid intake, and fluid output; blood tests must be done weekly.

Artificial delivery of food and water is regarded as medical treatment by the medical profession and the Federal Government. According to the American Academy of Neurology: "The artificial provision of nutrition and hydration is a form of medical treatment . . . analogous to other forms of life-sustaining treatment, such as the use of the respirator. When a patient is unconscious, both a respirator and an artificial feeding device serve to support or replace normal bodily functions that are compromised as a result of the patient's illness." The Federal Government permits the cost of the medical devices and formulas used in enteral feeding to be reimbursed under Medicare. The formulas are regulated by the federal Food and Drug Administration as "medical foods," and the feeding tubes are regulated as medical devices.³⁰

The colloquial, non-technological, "non-treatment" analog to medically supplied nutrition and hydration is food and water. Today, a patient with decision-making capacity is widely recognized as having the right to voluntarily refuse food and water by mouth when he or she nears death.³¹ For example, a late-stage cancer patient with decision-making capacity can not only refuse all chemotherapy and other potentially curative treatments, but can also refuse all attempts to feed him or her by mouth until he or she expires, likely through dehydration rather than starvation.³²

This contrasts markedly with the way Justice Scalia viewed food and water in *Cruzan*. He made plain in his concurrence his view that a person, even an ill one, refusing food and water could be force-fed; otherwise, the person would be committing suicide.³³ Now, however, medical ethicists concur that a person with capacity cannot be force-fed if there is a medical reason for the refusal.³⁴ Even a prisoner can refuse all nutrition and hydration, medically supplied or not, if doing so for reasons of illness.³⁵ State interests may outweigh a prisoner's right to refuse if the prisoner is refusing food and water as a protest or an attempt to obtain some special

30. *Id.* at 307–08 (Brennan, J., dissenting) (citations omitted).

31. See Paul T. Menzel, *Voluntarily Stopping Eating and Drinking: A Normative Comparison with Refusing Lifesaving Treatment and Advance Directives*, 45 J.L. MED. & ETHICS 634, 634–46 (2017); Thaddeus Mason Pope, *Legal Briefing: Brain Death and Total Brain Failure*, 25 J. CLINICAL ETHICS 245, 246 (2014) [hereinafter Pope, *Legal Briefing*]; Timothy E. Quill, *Voluntary Stopping of Eating and Drinking (VSED), Physician-Assisted Death (PAD), or Neither in the Last Stages of Life? Both Should Be Available as a Last Resort*, 13 ANNALS FAM. MED. 408, 408–09 (2015).

32. Cf. Quill, *supra* note 31, at 408–09.

33. *Cruzan*, 497 U.S. at 293 (Scalia, J., concurring).

34. Menzel, *supra* note 31, at 636 (explaining that, at one time, it was likely that the person refusing food and water would be deemed to lack decision-making capacity despite the existence of solid arguments that he or she did not lack such capacity).

35. MEISEL ET AL., *supra* note 5, § 5.04[F][1].

treatment, but they will not outweigh it if the reason the prisoner is refusing food and water is the proximity of death.³⁶

This is recognition of people as masters of their own destiny, as being truly able to control the ends of their lives. Withholding or withdrawal of medically supplied nutrition and hydration and voluntarily stopping eating and drinking both involve the right to say “no,” so some might consider both to represent informed-consent-based autonomy in decision-making. Only one, however, involves a refusal of *treatment*. Whereas the Court in *Cruzan* determined whether Ms. Cruzan’s parents were refusing treatment to determine whether there was a constitutional right to refuse, clinicians today recognize the rights of patients with capacity to refuse even food and water, which do not constitute medical treatment. What is at issue is not a right to refuse medical treatment, but a right to make a decision to control the end of life. Because patients without capacity retain the same constitutional rights as patients with capacity,³⁷ surrogates must be able to exercise incapacitated patients’ rights to refuse food and water by mouth.³⁸

In fact, now that clinicians frequently honor voluntary refusals of food and water by patients with capacity, some patients, especially those with Alzheimer’s Disease diagnoses, are writing advance directives refusing food and water by mouth when they reach late-stage dementia.³⁹ States may attempt to assert state interests to limit the exercise of such a right, as they do in some cases involving prisoners with decision-making capacity, but Justice O’Connor provided some insight into whether those assertions will be constitutional. In her concurrence, she emphasized that the Court in *Cruzan* did not “decide the issue whether a State must also give effect to the decisions of a surrogate decision-maker. In my view, such a duty may well be constitutionally required to protect the patient’s liberty interest in refusing medical treatment.”⁴⁰ The execution of an advance directive evidencing the patient’s choice of surrogate decision-maker, she said,

may be a valuable additional safeguard of the patient’s interest in directing his medical care. Moreover, as patients are likely to select a family member as a surrogate, giving effect to a proxy’s decisions

36. *Id.* § 5.04[F][1], at 5-60.

37. *Id.* § 2.05, at 2-18 (“[T]here is still more than a grain of truth to that view . . .”).

38. See *Cruzan*, 497 U.S. at 273 (majority opinion) (describing *Quinlan* as “[r]easoning that the right of self-determination should not be lost merely because an individual is unable to sense a violation of it”).

39. Thaddeus Mason Pope, *Whether, When, and How to Honor Advance VSED Requests for End-Stage Dementia Patients*, 19 AM. J. BIOETHICS 90, 90-97 (2019); Thaddeus Mason Pope, *Voluntarily Stopping Eating and Drinking*, 6 NARRATIVE INQUIRY BIOETHICS 75, 75-77 (2016); see also Julie Christenson, *An Ethical Discussion on Voluntarily Stopping Eating and Drinking by Proxy Decision Maker or by Advance Directive*, 21 J. HOSPICE & PALLIATIVE NURSING 188, 188-92 (2019).

40. *Cruzan*, 497 U.S. at 289 (O’Connor, J., concurring) (citation omitted).

may also protect the “freedom of personal choice in matters of . . . family life.”⁴¹

Thus, she instructed that the Court’s decision in *Cruzan* did “not preclude a future determination that the Constitution requires the States to implement the decisions of a patient’s duly appointed surrogate.”⁴² Justice O’Connor in *Cruzan* provided a blueprint for arguing that it would be unconstitutional to prevent a patient’s appointed surrogate decision-maker from refusing food and water by mouth on the patient’s behalf.

III. FROM PERSISTENT VEGETATIVE STATE TO MINIMALLY CONSCIOUS STATE

No one involved in *Cruzan*, including her guardian ad litem, questioned whether Nancy Cruzan was in a PVS.⁴³ The same was true of Karen Ann Quinlan at the time of her seminal case on withholding or withdrawal of life-sustaining treatment in 1976.⁴⁴ Trust in medical professionals may not have been as complete as it was before the development of informed consent as a legal doctrine,⁴⁵ but no one disputed those diagnoses. Indeed, the trial court in *Cruzan* found, “and no party contested, that Nancy [had] no possibility of recovery and no consciousness.”⁴⁶

At the time of *Cruzan*, medical professionals—at least those involved in that lawsuit—thought they understood the PVS. Based on uncontradicted medical evidence,⁴⁷ the Supreme Court majority in *Cruzan* described the PVS as “a condition in which a person exhibits motor reflexes but evinces no indications of significant cognitive function.”⁴⁸ Justice Brennan described Ms. Cruzan’s “irreversible persistent vegetative

41. *Id.* at 291–92 (citation omitted) (quoting *Cleveland Bd. of Educ. v. LaFleur*, 414 U.S. 632, 639 (1974)).

42. *Id.* at 292.

43. COLBY, *supra* note 26, at 135 (Ms. Cruzan’s guardian ad litem sided with her legal team); see also Joseph T. Giacino, *The Vegetative and Minimally Conscious States: Consensus-Based Criteria for Establishing Diagnosis and Prognosis*, 19 *NEUROREHABILITATION* 293, 294 (2004) [hereinafter Giacino, *The Vegetative and Minimally Conscious States*] (a person in a PVS has suffered devastation of the cerebral cortex (otherwise known as the higher brain) but his or her brainstem continues functioning, enabling such actions as reflex motions and sleep-wake cycles).

44. *In re Quinlan*, 355 A.2d 647, 654 (N.J. 1976) (discussing the consensus among experts on Ms. Cruzan’s case).

45. Jonathan F. Will, *A Brief Historical and Theoretical Perspective on Patient Autonomy and Medical Decision Making: Part I: The Beneficence Model*, 139 *CHEST* 669–70 (2011); Jonathan F. Will, *A Brief Historical and Theoretical Perspective on Patient Autonomy and Medical Decision Making: Part II: The Autonomy Model*, 139 *CHEST* 1491, 1491–92 (2011).

46. *Cruzan*, 497 U.S. at 345 (Stevens, J., dissenting).

47. Dr. Ronald Cranford examined the patients and testified in many cases about withholding or withdrawal of life-sustaining treatment with respect to patients in a PVS. Ivan Oransky, *Obituary: Ronald E. Cranford*, 368 *LANCET* 112 (2006); see also Steven H. Miles, *Ronald Cranford, MD, a Leading Neurologist on Coma and Unconsciousness, Dies at 65*, *MEDSCAPE*, <https://www.medscape.com/viewarticle/533952> [https://perma.cc/N8J8-EBBF] (last visited Feb. 19, 2020).

48. *Cruzan*, 497 U.S. at 261 (majority opinion).

state”⁴⁹ as “a twilight zone of suspended animation where death commences while life, in some form, continues.”⁵⁰ He said Ms. Cruzan was “oblivious to her surroundings and [would] remain so.”⁵¹

Her body twitches only reflexively, without consciousness. The areas of her brain that once thought, felt, and experienced sensations have degenerated badly and are continuing to do so. The cavities remaining are filling with cerebro-spinal fluid. The “cerebral cortical atrophy is irreversible, permanent, progressive and ongoing.”⁵²

In short, he said, “Nancy will never interact meaningfully with her environment again.”⁵³

That much is still true; it would be difficult to find a medical professional to opine that a patient in an irreversible PVS for more than seven years (as Ms. Cruzan was) had any chance of future meaningful interaction with her environment.⁵⁴ Modern neurology has determined that a vegetative state (VS), which should not be diagnosed until one month post-injury,⁵⁵ should not be categorized as “persistent” or “permanent.”⁵⁶ Instead, temporal characteristics determine when the VS is considered to be permanent; the temporal dividing line is twelve months after a traumatic brain injury and three months after a nontraumatic (hypoxic-ischemic) brain injury.⁵⁷ Many state statutes listing the PVS as a physical triggering condition for advance directives use the term “irreversible” in conjunction with “persistent vegetative state” to express the same concept.⁵⁸

Some families of patients in the irreversible PVS, however, cling to hope well beyond those time frames. Widespread publicity of “miracle

49. *Id.* at 303 (Brennan, J., dissenting).

50. *Id.* at 301 (quoting *Rasmussen v. Fleming*, 741 P.2d 674, 678 (1987) (en banc)).

51. *Id.*

52. *Id.* (quoting *Cruzan v. Harmon*, 760 S.W.2d 408, 411 (Mo. 1988)).

53. *Id.* (quoting *Cruzan*, 760 S.W.2d at 422).

54. Giacino, *The Vegetative and Minimally Conscious States*, *supra* note 43, at 295.

55. *Id.* at 294.

56. *Id.*

57. *Id.* at 295 (explaining that after a traumatic brain injury (TBI), remaining in a VS for more than one year (twelve months) is permanent, and after non-TBI (hypoxic-ischemic injury), three months constitutes permanence); *see also* James L. Bernat, *Chronic Consciousness Disorders*, 60 ANN. REV. MED. 381, 386 (2009); Carol E. Fisher & Paul S. Appelbaum, *Diagnosing Consciousness: Neuroimaging, Law, and the Vegetative State*, 38 J.L. MED. & ETHICS 374, 377 (2010) (noting broadly that many state statutes “typically contain quasi-operationalized definitions of ‘permanent unconsciousness’ or VS, which often do not correspond to the current clinical understanding of these diagnoses”); Multi-Society Task Force on PVS, *Medical Aspects of the Persistent Vegetative State (First of Two Parts)*, 330 NEW ENG. J. MED. 1499, 1499 (1994). A hypoxic-ischemic injury is one that is nontraumatic, with neurons in the brain being damaged from lack of oxygen. Bernat, *supra*, at 386.

58. For example, Florida’s statutory definition of “persistent vegetative state” is “a permanent and irreversible condition of unconsciousness in which there is: (a) [t]he absence of voluntary action or cognitive behavior of any kind[:]; [and] (b) [a]n inability to communicate or interact purposefully with the environment.” FLA. STAT. ANN. § 765.101(15) (West 2015).

recoveries”⁵⁹ fuel denial and increasingly vocal pro-life activists often support that denial.⁶⁰ Diagnoses of PVS have become a bit more controversial since *Cruzan*, as exemplified by a famous series of cases and legislative action involving Theresa Marie Schiavo, which concluded almost thirty years after *Quinlan* and fifteen years after *Cruzan*.

Ms. Schiavo had been found unresponsive in her home at the age of twenty-seven, apparently as a result of a cardiac arrest depriving her brain of oxygen and leaving her in a PVS.⁶¹ Despite intensive treatment including an experimental thalamic implant, Ms. Schiavo remained in a PVS three years later, when her parents and her husband began to disagree about her care.⁶² Her husband, Michael Schiavo, believed that Ms. Schiavo would want to stop life-sustaining treatment, while her parents wanted treatment to continue.⁶³ Although it initially seemed as if her parents agreed with medical experts and the court that Ms. Schiavo lay in a PVS, they began to question that diagnosis during the ongoing dispute.⁶⁴ For the next seven years, through litigation, legislation, and governmental agency action, Ms. Schiavo's parents argued that she was partially aware, claiming that she was in a minimally conscious state (MCS), although they did not use that terminology.⁶⁵

The MCS differs significantly from the PVS, not only medically, but also legally.⁶⁶ Medically, the MCS's name reveals the major difference. Whereas patients in the PVS are not conscious at all, patients in the MCS have some level of consciousness ranging from MCS-minus (barely con-

59. See, e.g., Palko Karasz & Christopher F. Schuetze, *Woman Wakes After 27 Years Unconscious*, N.Y. TIMES (Apr. 24, 2019), <https://www.nytimes.com/2019/04/24/world/middleeast/woman-coma-27-years.html> [<https://perma.cc/R4AF-7VJX>] (describing the awakening of a patient who had been in a minimally conscious state for twenty-seven years).

60. See Kathy L. Cerminara, *Collateral Damage: The Aftermath of the Political Culture Wars in Schiavo*, 29 W. NEW ENG. L. REV. 279, 281 (2007) [hereinafter Cerminara, *Collateral Damage*] (describing influence of pro-life activists on the lawsuit).

61. Kathy L. Cerminara, *Theresa Marie Schiavo's Long Road to Peace*, 30 DEATH STUDIES 101, 102 (2006).

62. *Id.* at 102–03 (noting disagreements began by “early 1993”).

63. The only life-sustaining treatment Ms. Schiavo was receiving at that time was medical administration of nutrition and hydration in the form of fluids injected into her body through tubes, which is significant itself, as discussed earlier in this article. *Id.* at 103 (“She required no other technologically advanced life-sustaining treatment.”).

64. The trial court judge ruled that Ms. Schiavo existed in a PVS “beyond all doubt.” *Id.* at 104. Near the end of Ms. Schiavo's life, her parents filed a motion contending that two people had heard her say, “I want to live.” *Id.* at 110.

65. See Cerminara, *Collateral Damage*, *supra* note 60, at 281 (describing the shift in argument). This primarily occurred before neurologists coined the term “minimally conscious state.” As neurologists recognized that condition, first defined in 2002, there came “the realisation that significant numbers of patients previously thought to be permanently unconscious might instead be conscious, although they exhibit little behavioural evidence of conscious awareness.” L. Syd M. Johnson, *The Right to Die in the Minimally Conscious State*, 37 J. MED. ETHICS 175, 175 (2011) [hereinafter Johnson, *The Right to Die in the Minimally Conscious State*]. Such patients are considered to have “covert consciousness.” *Id.*

66. Kathy L. Cerminara & Joseph R. Kadis, *Give Me Liberty to Choose (a Better) Death: Respecting Autonomy More Fully in Advance Directive Statutes*, 10 ST. LOUIS U. J. HEALTH L. & POL'Y 67, 87–89 (2016).

scious) to MCS-plus (some activity and possible interaction).⁶⁷ Legally, the fact that consciousness exists has led courts thus far to review requests for withholding or withdrawal of life-sustaining treatment in MCS-patient cases far more stringently than in PVS-patient cases.⁶⁸

Ms. Schiavo's parents were arguing that she was in an MCS rather than the PVS.⁶⁹ Late in the series of conflicts characterizing the case, they submitted affidavits claiming that Ms. Schiavo had uttered intelligible words: "I want to live."⁷⁰ Ms. Schiavo's autopsy⁷¹ later revealed that she could not have been as aware as her parents had argued. Her brain weighed only 615 grams (1.35 pounds), which was less than half the weight expected in a person her size.⁷² She was cortically blind, thus unable to follow objects or make eye contact with others, as her parents had argued.⁷³ While an autopsy cannot determine whether a person was in a PVS before death,⁷⁴ her autopsy could and did demonstrate that the physical portions of her brain necessary for consciousness simply were not present.

In cases involving patients with less brain damage, however, this scientific progress since *Cruzan* has done more than its fair share of encouraging fears and denial with regard to withholding and withdrawing life-

67. L. Syd M. Johnson & Kathy L. Cerminara, *All Things Considered: Surrogate Decision-Making on Behalf of Patients in the Minimally Conscious State*, CLINICAL ETHICS, May 27, 2020, at 1; J.T. Giacino et al., *The Minimally Conscious State: Definition and Diagnostic Criteria*, 58 AM. ACAD. NEUROLOGY 349, 349–53 (2002); Giacino, *The Vegetative and Minimally Conscious States*, *supra* note 43, at 294.

68. See, e.g., *In re Wendland*, 28 P.3d 151 (Cal. 2001); *In re Martin*, 538 N.W.2d 399 (Mich. 1995); *In re Edna M.F.*, 563 N.W.2d 485 (Wis. 1997).

69. Kathy L. Cerminara, *Law, Perception, and Cultural Cognition Near the End of Life*, 55 WASHBURN L.J. 597, 603 (2016).

70. See *Timeline of Key Events Part 2*, U. MIAMI INST. BIOETHICS & HEALTH POL'Y, <https://bioethics.miami.edu/clinical-and-research-ethics/terri-schiavo-project/timeline-of-key-events/part-2/index.html> [https://perma.cc/3LYJ-XWMM] (last visited Jan. 27, 2020) (noting affidavit said Ms. Schiavo said, "I want to live").

71. JON R. THOGMARTIN, CHIEF MED. EXAM'R, 6TH JUDICIAL CIRCUIT OF FLA., REPORT OF AUTOPSY: THERESA SCHIAVO (June 13, 2005), available at https://bioethics.miami.edu/_assets/pdf/ethics/Documents/documents/schivao/061505-autopsy.pdf [https://perm.cc/3T3F-TL5J].

72. Letter from Stephen J. Nelson, Chief Med. Exam'r, 10th Judicial Circuit of Fla., to J.R. Thogmartin, Chief Med. Exam'r, 6th Judicial Circuit of Fla. 5, available at https://bioethics.miami.edu/_assets/pdf/ethics/Documents/documents/schivao/061505-autopsy.pdf [https://perm.cc/3T3F-TL5J] ("The decedent's brain was grossly abnormal and weighed only 615 grams (1.35 lbs.). That weight is less than half of the expected tabular weight for a decedent of her adult age of 41 years 3 months 28 days. By way of comparison, the brain of Karen Ann Quinlan weighed 835 grams at the time of her death, after 10 years in a similar persistent vegetative state.").

73. *Id.* at 8.

74. *Id.* at 6, 8; Ronald Cranford, Commentary, *Facts, Lies, and Videotapes: The Permanent Vegetative State and the Sad Case of Terri Schiavo*, 33 J.L. MED. & ETHICS 363, 369 (2005) (describing a "strategy of misinformation" involving the use of videotapes originally created to assist the courts in understanding Ms. Schiavo's condition "to mislead much of the media and public into believing that Terri could meaningfully and cognitively interact with her parents and thus was not in a vegetative state"); see also Ronald E. Cranford, *A Common Uniqueness: Medical Facts in the Schiavo Case*, in THE CASE OF TERRI SCHIAVO: ETHICS, POLITICS, AND DEATH IN THE 21ST CENTURY 112–13 (Kenneth W. Goodman ed., 2010).

sustaining treatment. Disorders of consciousness, as neurologists term both the PVS and the MCS, are complex and poorly explained—if explained at all—in sound bites. Yet, sound bites are what families and friends have in mind when they discuss their loved ones' conditions with physicians and other medical personnel.

Today, diagnosis of a patient in an irreversible PVS as opposed to the MCS changes the legal analysis of end-of-life decision-making. Courts considering requests for withholding or withdrawal of life-sustaining treatment from patients in MCS have been stringent in requiring evidence to support claims that the patients would have wished to refuse that treatment.⁷⁵ Were the courts to treat patients in PVS as they have treated patients in the MCS thus far, it would be far more difficult for their loved ones to free them from their prisons in a "twilight zone."⁷⁶

Those were cases in which patients had not executed written advance directives, leaving their families to make decisions for them by operation of law rather than patient designation.⁷⁷ One might think that patients designating surrogate decision-makers would be better off, especially if recalling Justice O'Connor's instructions in *Cruzan* that the Constitution likely requires that clinicians and courts honor an appointed surrogate decision-maker's decisions.⁷⁸ To the contrary, however, a patient who has left a written advance directive specifying a surrogate decision-maker may inadvertently cause problems for himself or herself because of state statutes purporting to limit the situations in which that advance directive becomes effective.⁷⁹

Statutes in all states incorporate triggering conditions to limit the circumstances under which advance directives become effective. One common nonphysical limitation is that the advance directive is not effective unless a patient has lost decision-making capacity.⁸⁰ In addition to requiring incapacity, many statutes require that patients lie in specified physical conditions. The PVS is a common physical triggering condition, but no state statute lists the MCS as a physical triggering condition.⁸¹

Regardless of which view of autonomy governs, previous work has demonstrated that narrowly construing statutes to limit the right to patients in the PVS would violate the Constitution.⁸² Under either approach to autonomy, no state interests justify a state's imposition of continued

75. See, e.g., *In re Wendland*, 28 P.3d 151, 166 (Cal. 2001).

76. *Cruzan v. Dir., Mo. Dep't of Health*, 497 U.S. 261, 301 (1990) (Brennan, J., dissenting).

77. See *Wendland*, 28 P.3d at 156; *In re Martin*, 538 N.W.2d 399, 411 (Mich. 1995); *In re Edna M.F.*, 563 N.W.2d 485, 491 (Wis. 1997).

78. *Cruzan*, 497 U.S. at 289 (O'Connor, J., concurring).

79. Cerminara & Kadis, *supra* note 66, at 69–73; J. Clint Parker & Daniel S. Goldberg, *A Legal and Ethical Analysis of the Effects of Triggering Conditions on Surrogate Decision-Making in End-of-Life Care in the US*, 28 HEC F. 11, 12 (2016).

80. MEISEL ET AL., *supra* note 5, § 7.

81. Cerminara & Kadis, *supra* note 66, at 89.

82. *Id.* at 86–87.

treatment of a patient who will die relatively soon when that patient is in a condition he or she finds unbearable.⁸³

Diagnosis as being in the MCS or the PVS does, however, greatly affect the substantive factors the surrogate decision-maker should examine in determining whether a patient would have chosen to terminate treatment in the condition at hand. A patient in a PVS has no cognition; he or she is experiencing no life.⁸⁴ As Justice Brennan in *Cruzan* noted,

[T]reatment ordinarily aims to benefit a patient through preserving life, relieving pain and suffering, protecting against disability, and returning maximally effective functioning. If a prognosis of permanent unconsciousness is correct, however, continued treatment cannot confer such benefits. Pain and suffering are absent, as are joy, satisfaction, and pleasure. Disability is total and no return to an even minimal level of social or human functioning is possible.⁸⁵

Thus, reliance on a patient's perception of pain or anything else is inappropriate in cases of patients in the PVS. Although Justice Scalia described the petitioners in *Cruzan* as arguing that Ms. Cruzan was "permanently incapacitated and in pain,"⁸⁶ the descriptions written by the rest of the Justices are more accurate. A patient in a PVS would not experience pain.⁸⁷ A patient in the MCS, however, might experience pain or contemporaneous interactions at the bedside; indeed that is the type of clinical evidence that would be used to determine that they were in the MCS rather than the PVS.⁸⁸ To the extent it seems reliable, their consciousness must be a part of the decision-making calculations.⁸⁹

Considering a patient's likely experience in the MCS merely adds to the evidentiary possibilities; it does not rule out withholding or withdrawal of life-sustaining treatment. Many patients with decision-making capacity, such as those who refuse chemotherapy, are conscious when refusing life-sustaining treatment.⁹⁰ Patients who choose medical aid-in-dying are fully conscious—indeed, they must be fully conscious—at the time they end their lives.⁹¹ Being conscious of one's existence does not mean being content within that existence; it may mean more of a desire to end

83. *Id.*

84. One possible exception may be if covert consciousness becomes well-accepted as occurring. Joseph J. Fins & James L. Bernat, *Ethical, Palliative, and Policy Considerations in Disorders of Consciousness*, 91 *NEUROLOGY* 471, 471–75 (2018).

85. *Cruzan v. Dir., Mo. Dep't of Health*, 497 U.S. 261, 310 (1990) (Brennan, J., dissenting) (quoting PRESIDENT'S COMMISSION FOR THE STUDY OF ETHICAL PROBLEMS IN MEDICINE AND BIOMEDICAL AND BEHAVIORAL RESEARCH, *DECIDING TO FOREGO LIFE-SUSTAINING TREATMENT* 181–82 (1983)).

86. *Id.* at 295 (Scalia, J., concurring).

87. Giacino, *The Vegetative and Minimally Conscious States*, *supra* note 43, at 295–97 (explaining that there are "general physiologic responses to pain").

88. *Id.* at 294.

89. Cerminara & Johnson, *supra* note 67.

90. See, e.g., Moshe Frenkel, *Refusing Treatment*, 81 *ONCOLOGIST* 634, 634–35 (2013) (recounting story of Suzanna, a patient who refused chemotherapy).

91. HASTINGS CTR., *supra* note 28, at 59; see also, e.g., OR. REV. STAT. ANN. § 127.805 (West 2017).

that existence due to the limitations posed by the minimal nature of the MCS.⁹²

In sum, many variations in the exercise of autonomy may and should become more common if courts see more cases involving life-sustaining treatment decision-making for and with patients in the MCS. With the higher levels of MCS, there may even be a place for supported decision-making, a process intended to preserve whatever remains of the patient's ability to express himself or herself with some level of capacity.⁹³ Neurology clinicians have spoken of medical decision-making for patients in MCS as "mosaic decision-making," involving a patchwork of considerations gathered from a variety of resources, including the patient, to the extent possible.⁹⁴ Increasing understanding of the condition will develop the contours of autonomy in medical decision-making for patients in MCS, implicating both the approaches evident in *Cruzan* and expanding the amount of information appropriately considered.

IV. FROM DENIAL OF DEATH TO PROTESTS AGAINST ONE TYPE OF DEATH

Nancy Cruzan was in a PVS at the time of her lawsuit.⁹⁵ Her tombstone reads: "Departed, Jan. 11, 1983; At Peace, Dec. 26, 1990."⁹⁶ In November 1990, a reporter described her as having died in 1983 "at a time and in a place that [did] not recognize her death."⁹⁷

Legally, of course, Ms. Cruzan was not dead until December 26, 1990; her case revolved around the question of whether doctors legally could withdraw her medically supplied nutrition and hydration so that she could die.⁹⁸ A person in a PVS is not legally dead; in every state in this country, the law provides that physicians may declare death only when (1) the patient ceases respiration and circulation (known as "cardiac death") or (2) the patient's entire brain, including the brainstem, has ceased functioning (known as "death by neurological criteria" or "brain death").⁹⁹

Brain death does, however, present an intriguing puzzle when considering its interaction with autonomy. While one might normally think that

92. Johnson, *The Right to Die in the Minimally Conscious State*, *supra* note 65, at 175.

93. Megan S. Wright, *End of Life and Autonomy: The Case for Relational Nudges in End-of-Life Decision-Making Law and Policy*, 77 MD. L. REV. 1062, 1127–28 (2018).

94. Joseph J. Fins, *Mosaic Decisionmaking and Reemergent Agency After Severe Brain Injury*, 27 CAMBRIDGE Q. HEALTHCARE ETHICS 163, 169–70 (2018).

95. *Cruzan v. Dir., Mo. Dep't of Health*, 497 U.S. 261, 266 (1990).

96. Sara Taub, *Departed, Jan 11, 1983; At Peace, Dec 26, 1990*, AMA J. ETHICS (Nov. 2001), <https://journalofethics.ama-assn.org/article/commemorative-issue-departed-jan-11-1983-peace-dec-26-1990/2001-11> [<https://perma.cc/42XN-L6HG>].

97. *Id.* (quoting Richard Momeyer, *Finally, Let's Admit Nancy Cruzan Is Dead*, NEWS-DAY, Apr. 16, 1990, at 43).

98. *Cruzan*, 497 U.S. at 267–69.

99. See MEISEL ET AL., *supra* note 5, § 1A.22, at 1A-165. But see Jeffrey B. Hammond, *The Minimally Conscious Person: A Case Study in Dignity and Personhood and the Standard of Review for Withdrawal of Treatment*, 55 WAYNE L. REV. 821, 830 (2009) (arguing that the law should permit medical determination of death when a patient is in a PVS).

“death is death,”¹⁰⁰ it actually is a social construct, a societal judgment involving far more than medicine.¹⁰¹ The factors other than medicine involved in determining death imply that a person’s choice should play a role in whether to be dead.

A. DEATH AS A SOCIAL CONSTRUCT

Brain death has a fifty-year history in the United States. In 1968, an ad hoc committee at the Harvard Medical School (the Committee) took various medical and social factors into account in determining that it was medically appropriate for physicians to declare people dead when all portions of their brain had ceased functioning.¹⁰² Improvement in cardiopulmonary resuscitation techniques and respiratory support had increased the number of people with no brain function occupying hospital beds.¹⁰³ Moreover, the Committee said, “Obsolete criteria for the definition of death can lead to controversy in obtaining organs for transplantation.”¹⁰⁴

Among the public, confusion and much debate surround brain death. It is easy, if painful, to understand that a person is dead when he or she is not breathing, but both patients in the PVS who lack only higher brain function and patients with no brain function breathe and appear to be in the same condition, thanks to technology.¹⁰⁵ Thus, it is easy for people without medical backgrounds to believe they are the same.¹⁰⁶ While the reporter who described Ms. Cruzan as being dead in 1983 was speaking metaphorically,¹⁰⁷ many families have a hard time telling the difference, given the similar appearance of patients in the two categories.¹⁰⁸ The media compounds the problem by using the names of various neurological diagnoses, including brain death, interchangeably.¹⁰⁹

Similarly, but for different reasons, medical, ethical, and legal experts have debated the recognition of brain death as legal death from the 1960s through the present day.¹¹⁰ “Brain death has always been a bit suspect to

100. See Ackerman, *supra* note 20, at 1579–80.

101. Ben A. Rich, *Distinguishing Minimal Consciousness from Decisional Capacity: Clinical, Ethical, and Legal Implications*, 4 *AJOB NEUROSCIENCE* 56, 56 (2014).

102. Ad Hoc Committee of the Harvard Medical School to Examine the Definition of Brain Death, *A Definition of Irreversible Coma*, 205 *JAMA* 337, 337 (1968) (“More than medical problems are present. There are moral, ethical, religious, and legal issues.”).

103. *Id.*

104. *Id.*

105. Erwin J.O. Kompanje, *Families and Brain Death*, 35 *SEMINARS NEUROLOGY* 169, 170 (2015) (“[T]he significance of a beating heart remains important for some relatives.”).

106. *Id.* at 169 (“There are for some just too many signs of life, and some may not take the news at face value.”).

107. Momery, *supra* note 97, at 43.

108. Stuart J. Youngner & Elizabeth O’Toole, *Withdrawing Treatment in the Persistent Vegetative State*, 331 *NEW ENG. J. MEDICINE* 1382, 1382 (1994); cf. *In re Quinlan*, 355 A.2d 647, 652 (N.J. 1976) (New Jersey Supreme Court took pains to explain that Ms. Quinlan’s PVS was not brain death, emphasizing that Ms. Quinlan was not dead).

109. Kompanje, *supra* note 105, at 170 (providing examples).

110. See generally Pope, *Legal Briefing*, *supra* note 31, at 245 (explaining varying positions among experts while discussing the legal status of brain death).

some, due in part to philosophical and religious objections but also due to its utilitarian roots.”¹¹¹

In contrast, state legislatures have embraced the concept of brain death. Physicians in all fifty states may declare death based on either cessation of cardiopulmonary functioning or total absence of activity in the entire brain, including the brain stem.¹¹² The law treats the question of whether a patient is dead as one of fact to be determined by physicians, yet state laws vary in delineating when a physician may declare a patient dead, suggesting that death cannot be determined “by *discovering*, as an objective, scientific fact of the matter, but rather . . . by *deciding*, through a social consensus hopefully supported by the most reliable scientific information.”¹¹³

At the time of *Cruzan*, then, the law had long recognized brain death and did not consider it to be a controversial diagnosis. The tables have turned since *Cruzan*: brain death sparks great controversy while PVS has become a relatively routine diagnosis underlying refusals of life-sustaining treatment.¹¹⁴

B. PUSHBACK AGAINST BRAIN DEATH DECLARATIONS

Beginning in the 2010s, brain-death declarations, previously rarely contested, increasingly became the subjects of protests and even litigation.¹¹⁵ Some were religious objections to the diagnosis.¹¹⁶ In New York in 2019, for example, a trial court judge required that a hospital vacate a death certificate issued on the basis of brain death when it found that the hospital had failed to reasonably accommodate the religious beliefs of the pa-

111. Kathy L. Cerminara, *Rip Currents: Rough Water for End of Life Decision Making*, 21 J. HEALTH CARE L. & POL’Y 59, 64 (2018) [hereinafter Cerminara, *Rip Currents*].

112. MEISEL ET AL., *supra* note 5, § 6.04[A], at 6-111.

113. Ben A. Rich, *Structuring Conversations on the Fact and Fiction of Brain Death*, 14 AM. J. BIOETHICS 31, 31 (2014); *see also* Don Marquis, *Death as a Legal Fiction*, 14 AM. J. BIOETHICS 28, 28 (2014).

114. *See* MEISEL ET AL., *supra* note 5, § 6.04[A][1][a] (lengthy table of cases involving withholding or withdrawal of life-sustaining treatment from patients in PVS); *id.* § 1A.36[E], at 1A-250 (Supp. 2019) (“[B]rain death was infrequently if at all litigated when the third edition appeared, whereas it has been featured as a topic of importance in five of the past seven supplements . . .”).

115. Cerminara, *Rip Currents*, *supra* note 111, at 61, 65. *But see* MEISEL ET AL., *supra* note 5, § 1A.35[E], at 1A-250 (“It is likely impossible to determine whether objections to declarations of brain death are increasing or whether more are being publicized due to a variety of social forces, including the power of social media . . .”).

116. *See* N.J. STAT. ANN. § 26:6A-5 (West 1991) (requiring use of respiratory-cardiac death when conscientious objections to death by neurological criteria exist); 10 N.Y. COMP. CODES R. & REGS. tit. 10, § 400.16 (2018) (requiring policies and procedures for reasonable accommodation of objections to death by neurological criteria); *see also* CAL. HEALTH & SAFETY CODE § 1254.4 (West 2009) (providing for a short period of reasonable accommodation in cases of religious and cultural objections); 210 ILL. COMP. STAT. ANN. 85/6.24 (West 2008) (requiring that hospitals take patients’ religious beliefs into account when determining time of death). *See generally* L. Syd M. Johnson, *The Case for Reasonable Accommodation of Conscientious Objections to Declarations of Brain Death*, 13 BIOETHICAL INQUIRY 105, 109 (2016) (advocating further adoption of statutes like New Jersey’s).

tient's family.¹¹⁷ New York regulations governing death by neurological criteria require hospitals to establish and implement written policies about determination of death, including reasonable accommodation of religious or moral objections to the determination.¹¹⁸ Finding that the hospital had not reasonably accommodated the family's religious beliefs, "the trial court ordered that they take all steps necessary to vacate the death certificate in question and to arrange for the issuance of a new death certificate showing the date the patient ceased circulatory and respiratory functions instead of the original date."¹¹⁹

Accommodation leads to confusion because it facilitates the existence of a seemingly impossible situation: a person can be dead in one state and not in another.¹²⁰ The case of Jahi McMath provides an excellent illustration, beginning with a California declaration that she was brain-dead after a tonsillectomy in 2013.¹²¹ Her family objected to the diagnosis and transferred her body to New Jersey, where the law prohibits declaration of brain death when conscientious objections to the diagnosis exist.¹²² Five years later, in 2018, Ms. McMath was pronounced dead after cessation of cardiopulmonary functions, and her family ended the several lawsuits they had filed over her death.¹²³ One of those lawsuits had sought to invalidate the death certificate in California while Ms. McMath's body was maintained in New Jersey.¹²⁴

Other objections to brain death may derive from a variety of sources. Some objectors simply may not believe that brain dead is a valid concept. Medical research, for example, has shown that wounds heal, infections are healed, and a fetus may be gestated within the body of a patient who has been declared brain-dead, leaving some to wonder what death means if these activities can take place after its declaration.¹²⁵ Others may be concerned about the speed with which patients are declared brain-dead based on publicity accorded medical resource shortages, including shortages of organs for transplantation.¹²⁶ Once a patient has been declared dead, there is no duty to continue treatment because "the patient

117. *Nakar v. N.Y. Presbyterian Hosp.*, No. 1780/2017 (N.Y. Sup. Ct. Jan. 15, 2019).

118. *See* 10 N.Y. COMP. CODES R. & REGS. tit. 10, § 400.16 (requiring policies and procedures for reasonable accommodation of objections to death by neurological criteria).

119. MEISEL ET AL., *supra* note 5, § 1A.36, at 1A-254.

120. *Id.* § 1A.35[E], at 1A-250-51.

121. *Id.* § 1A.22, at 1A-162; Certificate of Death: Jahi Kelis McMath (Cal. Dec. 12, 2013).

122. MEISEL ET AL., *supra* note 5, § 1A.22, at 1A-163; *see also* N.J. STAT. ANN. § 26:6A-5 (West 1991) (requiring use of respiratory-cardiac death when conscientious objections to death by neurological criteria exist).

123. MEISEL ET AL., *supra* note 5, § 1A.35[A], at 1A-245 (referring to "the New Jersey death certificate issued in June 2018"); Certificate of Death: Jahi Kelis McMath (N.J. June 22, 2018).

124. Complaint for Declaratory & Injunctive Relief at 55–56, *McMath v. State*, No. 15-CV-06042 (N.D. Cal. Dec. 12, 2016).

125. Pope, *Legal Briefing*, *supra* note 31, at 245; *see also* D. Alan Shewmon, *Constructing the Death Elephant: A Synthetic Paradigm Shift for the Definition, Criteria, and Tests for Death*, 35 J. MED. & PHIL. 256 (2010).

126. MEISEL ET AL., *supra* note 5, § 1A.35[E], at 1A-250.

is no longer a patient;" instead, it becomes a dead body.¹²⁷ Dead bodies are sources of organs for transplants, and some families may fear the need for an organ is prompting a conclusion that their loved one is dead even though he or she is rosy-cheeked and breathing, albeit through a ventilator.¹²⁸

Recent litigation over brain-death protests has moved from objecting to declarations of death, as in the case of Jahi McMath, to refusing consent to the testing required to determine brain death, as in the case of Aiden Hailu out of Nevada.¹²⁹ In *Hailu*, a twenty-year-old college student's death "upended the law of brain death in that state."¹³⁰ Nevada law had provided that death be determined "in accordance with [generally] accepted medical standards."¹³¹ The hospital in which Ms. Hailu was a patient first determined that she was not brain-dead after three electroencephalogram (EEG) tests¹³² but later declared her brain-dead after she failed an apnea test more than a month later.¹³³ Her father, who was her guardian, had objected to the administration of the apnea test and followed up by objecting to the declaration of death and seeking a temporary restraining order preventing the hospital from removing her life support equipment.¹³⁴

In declaring Ms. Hailu brain-dead, her hospital had used American Association of Neurology (AAN) guidelines, which it argued constituted the generally accepted medical standard.¹³⁵ The trial court ruled in favor of the hospital because those guidelines were generally accepted medical standards,¹³⁶ but those guidelines could have resulted (as indeed they did) in a different conclusion from an EEG examination looking for loss of whole-brain activity.¹³⁷ Therefore, the Nevada Supreme Court re-

127. Pope, *Legal Briefing*, *supra* note 31, at 246–47.

128. Kompanje, *supra* note 105, at 169–70 (quoting one family member as saying, "I see no difference. He is still breathing and his heart is beating."); *see also In re T.A.C.P.*, 609 So. 2d 588, 589 (Fla. 1992) (parents seeking declaration of brain death for their anencephalic infant so that they could donate the infant's organs).

129. *See In re Guardianship of Hailu*, 361 P.3d 524 (Nev. 2015).

130. MEISEL ET AL., *supra* note 5, § 1A.25[A], at 1A-196 (stating then that the case had "potentially" done so, but Nevada did indeed amend its brain death statute the following year, as seen in MEISEL ET AL., *supra* note 5, § 1A.29[C], at 1A-220).

131. NEV. REV. STAT. ANN. § 451.007(2)(a) (West 2017); *see also* § 451.007; UNIF. DETERMINATION OF DEATH ACT (UNIF. LAW COMM'N 1980).

132. *Hailu*, 361 P.3d at 525.

133. *Id.* at 525 n.3 ("An apnea test 'adds carbon dioxide to the patient's blood. A person with a functioning brain stem tries to breathe in response to the carbon dioxide. If the patient tries to breathe, you abort the test immediately and say the patient is not brain-dead.'" (quoting LESLIE C. GRIFFIN & JOAN H. KRAUSE, *PRACTICING BIOETHICS LAW* 106 (2015))).

134. *Id.* at 525. Thanks to informed consent law, patients' families may be learning more about the procedures physicians are performing on their loved ones, providing more opportunities for objection earlier in the process. MEISEL ET AL., *supra* note 5, § 1A.35[E], at 1A-250.

135. *Hailu*, 361 P.3d at 526.

136. *See id.* at 527–28.

137. *Id.* at 527 (A diagnosis of brain death follows the successful completion of a number of prerequisites. They include a clinical evaluation, neurological testing examining the absence of cerebral or brainstem function by testing the patient's reflexes, as well as imag-

versed, holding that the legislature intended to ensure that the brain was not functioning at all before declaration of death¹³⁸ and that the model act upon which the legislature had based its law had sought to achieve uniformity in diagnosis by requiring that determinations of death “‘be made in accordance with accepted medical standards,’ and applied and construed in a manner ‘uniform among the states which enact it.’”¹³⁹

The trial court, the state supreme court ruled, had erred by failing to consider whether AAN guidelines were generally accepted medical standards among all the states that adopted the same model act that Nevada had adopted; only then would they suffice to support a diagnosis of brain death.¹⁴⁰ It remanded the case to the trial court for additional evidence and reconsideration of whether a determination of death using the AAN guidelines would satisfy the state’s statutory test, resulting in legal uncertainty about determining brain death in Nevada.¹⁴¹

The Nevada legislature responded by amending its law. The Nevada statute on determination of death now provides as follows:

1. For legal and medical purposes, a person is dead if the person has sustained an irreversible cessation of:
 - (a) Circulatory and respiratory functions; or
 - (b) All functions of the person’s entire brain, including his or her brain stem.
2. A determination of death made under:
 - (a) Paragraph (a) of subsection 1 must be made in accordance with accepted medical standards.
 - (b) Paragraph (b) of subsection 1 must be made in accordance with the applicable guidelines set forth in:
 - (1) “Evidence-based Guideline Update: Determining Brain Death in Adults: Report of the Quality Standards Subcommit-

ing tests such as the electroencephalogram (EEG), the apnea test, and other ancillary diagnostic tests. Only after all other diagnostic criteria have been satisfied may the apnea test be performed. The apnea test is required for the diagnosis of brain death and involves disconnecting the patient from the ventilator and supplying oxygen via a nasal cannula. Any spontaneous respiratory efforts are noted and the partial pressure of arterial carbon dioxide (PaCO₂) is measured. Absent visualization of any respiratory efforts and a PaCO₂ over 60 mmHg (or in some cases, 20 mmHg over the baseline), the patient meets the criteria for brain death. An EEG is a useful confirmatory test for the diagnosis of brain death that involves connecting electrodes to the scalp and measuring electrical activity in the brain by recording summated synaptic potentials. An isoelectric or flat recording for thirty minutes confirms the diagnosis.); *see also* Zhe Chen et al., *An Empirical EEG Analysis in Brain Death Diagnosis for Adults*, 2 COGNITIVE NEURODYNAMICS 257 (2008); DEP’T OF SURGICAL EDUC., ORLANDO REG’L MED. CTR., BRAIN DEATH DETERMINATION/APNEA TESTING 1–5, http://www.surgicalcriticalcare.net/Guidelines/brain_death_determination_2009.pdf [https://perma.cc/5ZQM-83CE] (last updated Oct. 10, 2009); G. Bryan Young, *Diagnosis of Brain Death*, UPToDATE, <https://www.uptodate.com/contents/diagnosis-of-brain-death> [https://perma.cc/YEU8-X8JU] (last updated May 27, 2015).

138. *Hailu*, 361 P.3d at 532.

139. *Id.* at 529 (quoting NEV. REV. STAT. ANN. § 451.007(2)–(3) (West 2017)).

140. *Id.* at 532.

141. Siobhan McAndrew, *The Contested Death of Aden Hailu*, RENO GAZETTE J. (Mar. 25, 2016), <https://www.rgj.com/story/news/2016/03/25/contested-death-aden-hailu/82269006/> [https://perma.cc/YG4C-2L3E].

tee of the American Academy of Neurology,” published June 8, 2010, by the American Academy of Neurology, or any subsequent revisions approved by the American Academy of Neurology or its successor organization; or
 (2) “Guidelines for the Determination of Brain Death in Infants and Children: An Update of the 1987 Task Force Recommendations,” published January 27, 2012, by the Pediatric Section of the Society of Critical Care Medicine, or any subsequent revisions approved by the Pediatric Section of the Society of Critical Care Medicine or its successor organization.¹⁴²

In the new section (2)(b), the legislature specified particular medical guidelines “or any subsequent revision” of them for the medical profession to use in declaring death.¹⁴³ In response to that case and the legislature’s action, the AAN has issued a position statement calling for uniform brain death laws, policies, and practices.¹⁴⁴

Most other states have not amended their laws in the way Nevada has, meaning that here, too, as with accommodation of objections based on conscience, it may be possible to be dead in one state but not in another depending on the medical guidelines used. The resulting lack of specificity and uniformity is a source of concern for the AAN, which states that “[t]he medical profession’s ability to determine death accurately, whether caused by irreversible brain or circulatory failure, is integral to the maintenance of the public trust in the profession’s fulfillment of its fiduciary responsibility to its patients.”¹⁴⁵ In its statement, the AAN emphasizes that preserved neuroendocrine function, which can cause the physical changes after death described earlier, does not invalidate the whole brain standard of death and recommends some measures to enhance public trust and to deal with accommodation requests.¹⁴⁶

One might ask what protests against declarations of brain death have to do with views of autonomy. If brain death is indeed a social construct, then one might argue that the more expansive view of autonomy requires honoring the conception of death each person chooses in all cases. Such a conclusion suggests that the law and medicine should honor objections to brain-death declarations in many more cases than current practice permits. A decision to recognize neurologists’ definition of death or a more traditional definition of death involves “defin[ing] one’s own concept of existence” in somewhat the same way as a decision to continue or disconnect life-sustaining treatment does.¹⁴⁷ Yet honoring all objections to

142. NEV. REV. STAT. ANN. § 451.007.

143. *Id.* § 451.007(b).

144. James R. Russell et al., *Brain Death, the Determination of Brain Death, and Member Guidance for Brain Death Accommodation Requests*, 92 NEUROLOGY 228, 228 (2019); see also Sherri A. Braksick et al., *Variability in Reported Physician Practices for Brain Death Determination*, 92 NEUROLOGY 1, 1 (2019).

145. Russell et al., *supra* note 144, at 228.

146. *Id.* at 230–31.

147. *Washington v. Glucksberg*, 521 U.S. 702, 726–27 (1997) (quoting *Planned Parenthood v. Casey*, 505 U.S. 833, 851 (1992)).

brain-death declarations would go too far because doing so reduces death to the absurd. If the AAN is disturbed by the lack of public trust in brain-death declarations in the current situation, imagine how unmoored and untrustworthy the medical profession would seem if patient families could choose whether they had died.

Instead, limiting actionable objections to those arising from conscience or religion is sensible. The expansive view of autonomy will still require respect for both refusals of consent to apnea testing and protests against a diagnosis of brain death, but autonomy will be limited in the name of state interests in the trustworthiness of the medical profession. In the name of public trust, state interests should overwhelm a person's asserted right to choose whether to recognize brain death as death except in limited situations.

V. CONCLUSION

In conclusion, this article has identified three situations in which end-of-life decision-making autonomy faces legal development unimaginable at the time of *Cruzan*. Legislatures and courts have been and increasingly will be grappling with the definition of autonomy in instances of voluntarily stopping eating and drinking, refusals of life-sustaining treatment by patients in the MCS, and objections to declarations of brain death.

The Supreme Court since *Cruzan* has adopted two versions of constitutionally protected decision-making, both of which have roots in the *Cruzan* opinions. Justice O'Connor also suggested that constitutionally protecting autonomy in medical decision-making may require honoring a patient's appointed surrogate's end-of-life treatment decisions regardless of the strength or weakness of the patient's wishes. As clinical progress continues, we will see the law of medical end-of-life decision-making autonomy repeatedly invoke *Cruzan* in a broader range of settings. Ms. Cruzan's legacy in autonomy lives on.